




Families' Perceptions of Conflict of Interest in Organ Donation Discussions


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Overview

- * Background/phenomena of interest
- * Objective
- * Review of Literature
- * Methodology
- * Data Collection
- * Credibility
- * Findings
- * Discussion




Abbreviations & Definitions

NDD – Neurological Determination of Death
 CCDT – Canadian Association of Donation & Transplantation
 DCD – Donation after Cardiac Death
 REB – Research Ethics Board
 CNS – Clinical Nurse Specialist
 Decoupling – separating the donation discussion from the discussion of patient prognosis or death
 WLS – Withdrawal of Life Sustaining Therapy




Background & Phenomena of Interest

- * potential may be identified prior to NDD
- * concern clinician's practice influenced by potential
- * discussion with families prior to death perceived as conflict of interest by team in some settings
- * families' perceptions of timing of discussion and perception of conflict of interest unclear
- * findings have implications for optimal discussion and consent outcome, practice & policy



Objective:

To determine whether substitute decision makers perceive a greater degree of conflict of interest on the part of the health care team if discussions regarding organ donation begin prior to, rather than following declaration of brain death.



Review of the Literature

No direct research on perception of conflict of interest with donor families

Focus of previous research:

- * association of consent rates and understanding of brain death
- * association of consent rates with timing of the discussion (decoupling)
- * needs, stresses and coping strategies of families
- * reflection of the donor family experience



Literature cont'd

- * disparity between common understanding and clinical presentation of NDD
- * family understanding of NDD associated with consent rates
- * 'hastening death' concern polls/studies mixed
- * separation of treating physician from "ask"
- * legislation
 - pronouncement of death by 2 physicians
 - may not be associated with intended recipient
- * CCDT - NDD & DCD documents



Conflict of Interest & Donation

- * two roles conflict
- * situational (exists independent of action)
- * conflict can be mitigated - but it still exists
 - removal
 - disclosure
 - abstinence from further participation
 - third party involvement
 - code of ethics



Methodology

- * Qualitative Study with REB approval
- Participants: English speaking patient substitutes involved in an organ donation discussion will CNS or alternate
- * At time of discussion, ask permission to contact patient substitute(s) to participate
 - * Letter posted 80 days following discussion
 - * Independent researcher contact at 90 days
 - * Consent obtained
 - * Semi-structured telephone interviews



Interview Questions Excerpt

- * Please describe your experience
- * Whose interests do you feel the health care team caring for your loved one had in mind during your experience? Did you have doubts at any point about the team's interest in his/her welfare?
- * Whose interests do you feel the CNS had in mind/represented when she discussed organ donation with you?
- * Do you think the timing of the discussion about organ donation with the CNS influenced your thoughts about conflict of interest?



Credibility (Burns, 1996)

1. Descriptive vividness
2. Methodological congruence
3. Analytic Preciseness
4. Theoretical connectedness
5. Heuristic Relevance



Participants

- * 28 patient substitutes agreed to be contacted
- * 12 participated in interview
 - All participants had consented to donate, save one
- * Those who did not participate:
 - 1) contact information changed
 - 2) did not return phone calls of researcher
 - 3) changed mind about participating
 - 4) did not participate because they had not received police report they were promised



Data Collection

- * Transcripts reviewed by 2 researchers
- * Reviewed for themes and link to conflict of interest
- * Findings confirmed between researchers



The Participant's Experience

- * Shocked and confused
- * Hoping for the best
- * "relief we were in a trusted place"
- * Attentiveness of Staff



Quality of Care

- * Most participants stated it was "good" or "excellent"

Exceptions

- * "where was the care?"
 - family member of patient with sudden deterioration after successful surgery
- * "Communication not primary skill"



Focus of the Healthcare Team's Interest

- * Most had no doubts about focus of interest
"I'm sure that they did everything that they could, and no, I don't think I have any doubts about that."
- * Multiple interests
- * Shift in interests
"I mean, as soon as the doctor made up his mind that he was gone, I don't think he really cared about J. himself, more what he could do to help others."



Focus of the CNS

- * Donor Family
- * Multiple interests
"I think she (CNS) was representing both parties very well. She made it clear that our needs are first but also she had an objective view of it, which is good."
- * Source of information
"She had to explain to us that they still have to keep him breathing"



Perceptions - Conflict of Interest

- * No perceived conflict of interest with CNS or healthcare team members
"She was trying to encourage us to make a donation. We thought it was a good idea, but I didn't feel that she was forcing us or pressing us or anything."



Timing of Discussion

- * Just under half of discussions prior to NDD
 - Consent rate pre-NDD Discussion 66%
 - Consent rate post-NDD Discussion 75%
- * Most participants felt that it did not influence their decision
- * Never a “good” time for discussion
 - no suggestions for better timing
 - two participants reported feeling rushed



Family Members’ Decision

- * Donate everything that is “useful” or “all that can be helpful”
- * Donate with exceptions

“We donated the heart, lung, kidneys and liver. They mentioned anything else? I said “No, nothing else”. Today, I might make a different decision, but I certainly couldn’t then. This was too overwhelming.”



Meaning of Donation

- * Honoring family members wishes

“It was a completely euphoric experience to know that this was her decision.”
- * Giving another life and hope

“I explained it to my kids, because my mom died what a nice Christmas present for someone who’s waiting for an organ.”
- * Donation eased family’s suffering

“In our minds, part of her is living on. And I think that really helps with the healing process a lot. That’s helped my family a lot.”



Things we knew before

- * Donation is meaningful for grieving families, and can provide comfort
- * Families experience of quality of care is associated with the communication and perception of caring
- * Never a “good” time for the donation discussion
- * Families who chose not to donate, chose not to participate in donation research



What this study adds

- * Families’ who donate did not perceive a conflict of interest on the part of either the health care team or the CNS



Implications for Practice

- Caring & communication influence families’ experience at end-of-life
- Consideration should be given to having the donation discussion in advance of NDD as the patient may not meet all the criteria for NDD
- Regardless of perception, conflict of interest regarding organ donation needs to be addressed
 - Important for emerging practices such as DCD



Implications for Practice/Policy

Mitigation of conflict of interest

Removal: formal NDD or decision to WLST prior to introducing donation (DCD)

Disclosure: transparency related to multiple interests of donation & transplantation

Third party involvement: requester is not part of team involved in patient's care

Code of ethics/policy guidelines



Implications for Research

- * Do families who chose not to donate perceive a conflict of interest?
 - How do we involve families who chose not to donate in research?
- * Is it the 'understanding' or 'acceptance' of NDD that provides the watershed moment, not the actual formal pronouncement of death?
 - If we include "interest" in donation pre-NDD, consent rates are equal
- * What is the impact of conflict of interest mitigation practices on consent rates?



Thank you

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